

Managing Crisis Situations in Dementia Care



FACILITATOR GUIDE

Developed by:

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Center for Community Development, Engagement and Training (CCDET)

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Division of Quality Assurance

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Learning Points

After completing this workshop, learners will be able to:

- Identify behaviors that may lead to crisis situations
- Explain the importance of the caregiver's response
- Create responses based on the needs of the resident
- Manage crisis situations through three major steps

Introduction



As experienced caregivers know, difficult situations can occur when people with dementia or other cognitive disorders demonstrate unusual behavior. A situation can escalate into a full-blown crisis, sometimes dependent on the response of others.

When we recognize some common behaviors that are caused by the condition, it may be easier to manage or de-escalate crisis situations.

Just as important...when we understand our own behavior, we are more capable of determining a helpful response.

This workshop will explore some “reasons” behind behaviors that lead to crisis situations, both from the perspective of the resident and the caregiver, and offer responses to help de-escalate crisis situations.

Behaviors That May Lead to Crisis Situations

Keep in mind that challenging or unusual behaviors are based on faulty information to the brain, not necessarily bad manners.

[Ask the learners to review the list and be prepared to say which behaviors they think are most likely to lead to a crisis or another question that you prefer. Give them a few minutes until most seem ready. Ask for responses.]

Anger and agitation

We all have days when we feel stressed out. People living with dementia experience stress too and may lack the ability to relieve their stress in a healthy way. The result may be angry motions and words or agitation such as wringing hands, pacing, pounding on a table or other repetitive actions.

Aggression

Some people living with dementia may take anger and agitation a step further and become verbally aggressive or physically threatening. In some cases, a person living with dementia may strike out at a caregiver or family member due to fear, delusions or other faulty information provided by the brain.

Wandering

It is estimated that 60% of people living with dementia will wander. A person may not remember his or her name or address and can become disoriented, even in familiar places. A person living with dementia may be in search of an old neighborhood, job or other memory from the past.

Sleeplessness and Sundowning

Many people living with dementia experience periods of increased confusion at dusk, with their disorientation continuing throughout the night. These periods of what is known as 'sundowning' usually diminish as the dementia progresses. Sundowning may be caused by:

- mental and physical tiredness at the end of the day
- reduced lighting and an increase in shadows
- less need for sleep, common among older adults
- the body mixing up day and night

Inappropriate Sexual Behavior

Dementia can reduce inhibitions, which may affect an individual's private thoughts, feelings and behaviors – including those relating to sex. Sometimes people living with dementia may appear to lose their inhibitions and make sexual advances to others or undress or touch themselves in public. They may use language that seems out of character.

Inappropriate touching can result when people living with dementia confuse another person with a spouse or partner. It's important to note that inappropriate sexual behavior does not on its own make a person living with dementia a sexual predator.

Delusions or Hallucinations

Delusions are firmly held but false beliefs. People living with dementia may become convinced that a formerly trusted person is stealing from them or that they are being followed by the police. Negative delusions and beliefs of harm are also called paranoia. Memory loss and confusion can contribute to these untrue beliefs.

Hallucinations are different from delusions. Hallucinations are false perceptions involving the senses. A person living with dementia may see, hear, smell, taste or even feel something that isn't really there. The person may believe there are insects crawling on their arm or hear and respond to a person who isn't really there.

Not all delusions or hallucinations are negative and harmful to a person living with dementia. For example, a person may find that a "conversation" with a deceased relative is comforting.

Taking Things that Don't Belong To Them, "Collecting" Specific Items

When people living with dementia lose their sense of place, they may view items as their own, even when the items are located in another person's space. A person may be viewed as "stealing" when they have simply forgotten that the item belongs to another. In reality, the person may be repeating pleasurable activities from earlier in life, collecting items such as dolls or coins. Sometimes, the person may think of the behavior as "shopping." There is usually no intent to deprive the owner of his or her property.

Dressing Inappropriately

The person may forget how to dress, wearing layers of clothing in hot weather or going outdoors in cold weather without shoes. A person may also remove clothing at inappropriate times or in odd settings. For example, a woman may remove a shirt or slacks just because it is too tight or uncomfortable.

Personality Changes

People living with dementia may begin to do and say things they would never have before because their 'filter' is no longer stopping them. The 'filter' is that part of the brain that has told us what is appropriate and not appropriate to do and say. Other personality changes may be due to depression or anxiety that may accompany dementia.

Depression and anxiety can be treated with medications.

Becoming Lost-Even in Familiar Territory

It is very common for people living with dementia and Alzheimer's disease to lose a sense of their surroundings and mistake familiar locations for new territory or vice versa. Memory loss and confusion contribute to situations in which the person becomes easily lost. The person's skills may vary. For example, the person may have walked to the dining room and back yesterday, but may be unable to do so today.

Repetitive Behavior

Memory loss, fear and anxiety can cause a person living with dementia to repeat certain behaviors over and over. The person seems fixated on one idea or thought. This is sometimes called "perseveration" and may include:

- Asking repetitious questions
- Repeating phrases or movements
- Repeating actions
- Repeatedly asking to go home
- Making multiple phone calls

Shadowing

Anxiety, inability to cope or loneliness may lead a person living with dementia to closely follow another person everywhere they go. The person may be trying to communicate a need but unable to do so.

Day/Night Reversal

Many people living with dementia are restless at night and find it difficult to sleep. Older people often need less sleep than younger people. Dementia can affect people's body clocks so that they may be restless or awake all night, get up, get dressed or even go outside. Often the person will take catnaps during the day.

Confabulation

Confabulation means unconsciously replacing lost memories with fabricated or made-up information. When a person has dementia, whole experiences are lost, making it difficult for the brain to get its bearings. So the unconscious mind fills in the gaps, substituting

an old memory or coming up with a possible alternative. Confabulation is different from lying, when a person purposely gives untruthful information to another.

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Emotional Memory

As dementia progresses a person still experiences emotions, but may have less ability to regulate them due to changes in the brain. As a result, the person can be labeled as having irrational or inappropriate behavior. People living with dementia often forget the circumstances that caused a strong feeling originally. But they may retain those feelings they associated with the incident for a long time.

Transfer Trauma

Transfer trauma describes the stress that an individual living with dementia may experience when changing living environments. It is commonly seen in dementia patients who are moving into a facility from their long-time home in the community. For some, the stress associated with the move may be fairly significant and for others mild or not at all. This stress is usually temporary in nature and relieved as the individual builds friendships, gains trust, and develops a sense of purpose and belonging in their new community. However, if transfer trauma is not reduced, then negative consequences such as depression, anxiety, resistance to care and other challenging behaviors can occur.

Activity: Associate the Behavior with the Scenario

[Read or ask a volunteer to read each short scenario, one at a time. Ask the audience to review the behavior list and raise their hand to volunteer a response. Try to avoid calling on the same person—no matter how quickly they raise their hand.]

Jack constantly tells “tall tales,” and people tend to see him as a liar; someone to avoid.

[Confabulation]

Betty sometimes uses profanity and name-calling when speaking to her caregivers.

[Personality changes]

Maria, a domestic abuse survivor, recoils and cries when anyone tries to give her a hug.

[Emotional memory—Maria may not recall the abuse, but remembers the feelings.]

At dinnertime, Harold paces and seems anxious.

[Sundowning]

Charlotte asks when she can go home at least 10 times a day.

[Repetitive behavior]

Diego is often found “speaking” with his wife, who passed away years ago.

[Hallucinations]

Gerald was recently found sitting on the side of a female resident’s bed, attempting to kiss her goodnight.

[Inappropriate sexual behavior]

Angela has taken off most of her clothes and walked down to the activity room.

[Dressing inappropriately]

Mai has gotten all dressed up and is waiting for her birthday cake, although her birthday was last month.

[Delusions]

Larry is pacing up and down the hall, muttering to himself and pounding on the walls.

[Anger and agitation]

Brett views another male resident as a rival and starts an argument, leading to an altercation between the two.

[Aggression]

Mary insists that there are people following her, wanting to hurt her.

[Negative delusions; paranoia]

Responses to Crisis Situations



It usually takes two people to create a crisis. We have discussed some of the behaviors that a resident with dementia may present that can contribute to a crisis. Next, we will explore some common responses by caregivers that can actually escalate the situation.

Activity: Think of a Person in Your Care

Think of a person that you provide care for who is a joy to support. Write down some characteristics of that person.

[Give the learners a few moments to write down some choices. Ask for responses and record them on a flip chart or white board. Possible responses might include: cooperates, smiles, thanks me, does what they are asked.]

Next think of a person that you provide care for who you find difficult to support. Write down some characteristics of that person.

[Give learners a few moments to write down some choices. Ask for responses and record them on a flip chart or white board. Possible responses might include: uncooperative, refuses to follow directions, is grumpy, scowls at me.]

As you can see, differences usually come down to whether the person is cooperative (a joy) or uncooperative (difficult). It is up to the caregiver to be able to see behaviors as caused by the illness, not the personality.

Wanting Energy

As we grow and mature, we learn to be assertive – to get our needs and wants met in ways that demonstrate respect for ourselves and for others.

A term for the energy we expend getting our wants and needs met has been named, “**wanting energy**” by Mark Sweet, PhD.

People living with dementia may no longer be able to express their “wanting energy” in an appropriate manner. The caregiver’s “wanting energy” may conflict with that of the

person in their care. Conflict can worsen when the person living with dementia is unable to communicate wants and needs.

Consider an example of “wanting energy.”

As she has in the past, Caregiver Paula enters Robert’s room to get Robert up and ready for the day (expressing her wanting energy). In the box below, list what Paula might “want.” Robert scowls and grabs the blankets holding them close to his chin (expressing his wanting energy). In the box below list what Robert might “want”.

[Prepare a flip chart or white board with the chart below, leaving the responses blank. Ask learners to offer their ideas of what Paula and Robert might want. Fill in the table as they respond.]

Paula might “want” Robert to:	Robert might “want” Paula to:
<p><i>[Get ready so she can help the other residents assigned to her.</i></p> <p><i>Hurry because she is running late.</i></p> <p><i>Cooperate with her.]</i></p>	<p><i>[Sleep a little longer.</i></p> <p><i>Keep the blankets on because he is cold.</i></p> <p><i>Get up when he wakes up, not when Paula awakens him.]</i></p>

When “wanting energies” conflict, crisis situations can happen.

Belief Systems

We all know that our *belief system and attitudes* affect how we behave and interact with others. Let’s take a look at some beliefs that might impact how we respond to people living with dementia.

[If possible, break the audience into groups. Review the four beliefs briefly. Ask the group or individuals to write down their thoughts about each statement. Write their responses on a flip chart.]



“I know what’s best for the person in my care.”

This gives the caregiver unwritten “permission” to make all decisions for the person.

What thoughts do you have about this statement?

[Possible response: People living with dementia know their wants and have a right to have them respected.]



“Whatever action I take is acceptable because ‘I am only trying to help’.”

This belief excuses any behavior by the caregiver because the motive behind the behavior is noble.

What thoughts do you have about this statement?

[Possible response: It is important that the caregiver focus on how her behavior is received by the resident.]



“The resident won’t remember the incident anyway.”

This belief assumes that the behavior will have no effect on the resident.

What thoughts do you have about this statement?

[Possible Response: The person may remember the feeling experienced when the incident occurred.]

“It doesn’t matter what I say or do; nothing works!”

This belief gives the caregiver permission to give up.

What thoughts do you have about this statement?

[Possible Response: It is a caregiver’s responsibility to try everything possible to learn the person’s point of view in a given situation.]

It’s important to examine our personal beliefs to ensure they are not contributing to a crisis.

Power and Control



Caregivers are busy people! While trying to complete all their tasks in a given day, caregivers may send themselves the unspoken message that they must take control of the situation. This often leads to the ***imbalance of power and control*** between caregivers and those in their care.

The questions become, “Who is in charge?” “Who is in control?” “Whose wants are being considered?” “Whose point of view prevails?”

Seeing the relationship as one in which someone needs to be in control creates a climate of contest, in which one person wins and one person loses.

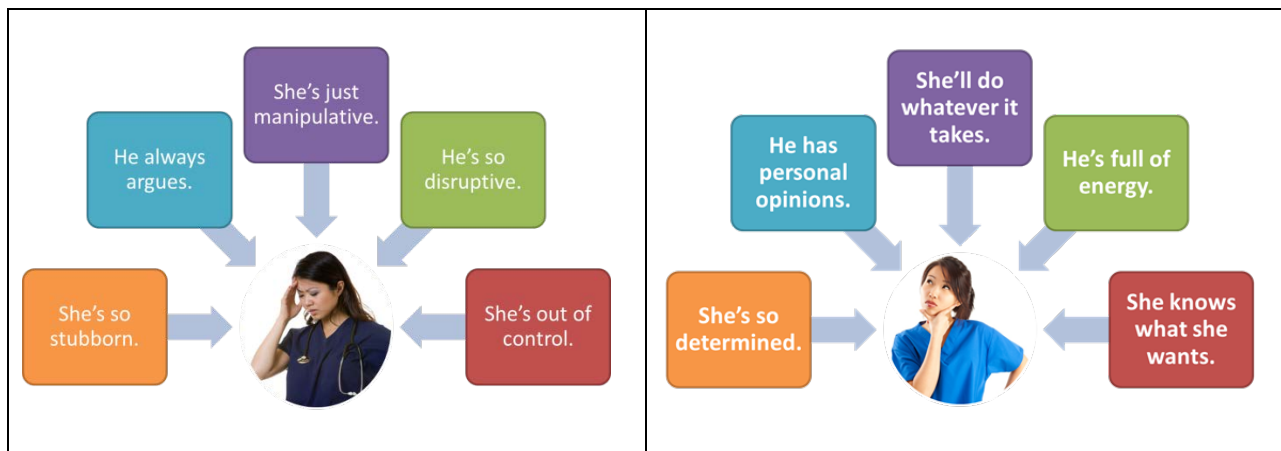
How do we balance the need to get the job done with the needs of the resident while avoiding a crisis?

New Approaches

Next, we will explore caring for people living with dementia from additional perspectives, with the goal of learning some new approaches to care and support.

Changing Your Point of View

There are often two different ways of viewing the behavior of a person in your care. Consider the pictures below.



When viewed with compassion, the resident's unusual behavior becomes a puzzle to solve rather than a behavior to control.

The Crisis Manager Hat



Sometimes we talk about people wearing different “hats” at work, meaning they play a variety of roles throughout their workday.

For caregivers, one of those roles may be as crisis manager, working to resolve difficult situations with residents. When a crisis occurs, a caregiver is not actually going to put on a hat! However, visualizing the “crisis manager hat” helps associate some actions that can de-escalate crisis situations.

In a crisis, the only behavior you control is your own. Your response to the crisis can escalate the problem or defuse a tense situation.



Step #1: Check Your Own Responses

Stop, slow down and breathe. Ask yourself:

- ✓ What are you thinking?
- ✓ What are you feeling physically?
- ✓ What are you feeling emotionally?

When we take these actions, we focus on our own behavior and become aware of how our verbal and non-verbal behaviors influence the person in our care. We are able to think more clearly and creatively as we plan our responses. What verbal and non-verbal behaviors should we adapt when approaching a crisis setting?

[Ask the learners for some responses. Possible responses: project a calm demeanor, speak slowly and clearly, approach carefully from the front, put away past impressions/opinions of the person. Record responses on a flip chart or white board.]



Step #2: Assess the Situation

Ask yourself the following questions. Note that these questions assume that you have some knowledge of the resident, their preferences, fears, etc.

- ✓ What do I see or hear?
- ✓ When is the person more likely to respond in this way?
- ✓ What does the person understand?
- ✓ What do you think the person might be feeling?
- ✓ What is the person trying to cope with, accomplish or assert?
- ✓ If the person could communicate clearly, what might they say?

The questions may seem too much to think about in a crisis. When they become associated with “putting on the hat”, they come more automatically. Asking these questions provides the caregiver with a framework to consider what the person with dementia might be trying to communicate; what might be their point of view.



Step #3: Take Action or Not?

Is the person's behavior unusual but not upsetting them or anyone else? Sometimes the best response is none at all. However, if the behavior spirals toward crisis, we must use everything we know about the person to help de-escalate the situation:

- ✓ Use re-direction or diversion to lessen the crisis. (Try to offer another choice to the person—what activities do they like, what spaces seem safe, is there a favorite snack or beverage?)
- ✓ Validate the person's assertions. (Avoid arguments with the person.)
- ✓ Say your name and ask the person if you can help.
- ✓ Use known techniques that normally calm the person. (Successful techniques should be documented and known to all staff.)
- ✓ Step away and re-approach later. (If there is no immediate harm, don't escalate the situation yourself.)
- ✓ Ask another caregiver to step in. (Are you the right person to approach the resident? Does the resident know you/normally have a good relationship with you?)
- ✓ Change the environment to calm the person. (Is it too loud, unfamiliar, chaotic?)
- ✓ Honor the person's sense of personal space. (People with dementia are often protective of their personal space and belongings.)
- ✓ Determine whether or not a medication side effect may be causing the behavior. (If you suspect a side effect, report it immediately to your supervisor.)

[Ask the learners if they have other ideas that they may have used. Document the ideas. Encourage learners to write them down.]

IMPORTANT NOTE: If the situation becomes violent, step away and seek help. You are not expected to subject yourself to injury.

Activity: Practice the Steps

Consider the following scenario:

[Ask for a volunteer to read each of the scenarios below. This helps auditory learners who may struggle with reading comprehension. If no one volunteers, read them yourself.]

The Resident

Julia is an 80-year old diagnosed with Alzheimer's disease. She has lived in a memory care unit for two years after moving from her home in the community. Julia's husband of 60 years, Robert, passed away last month. Julia doesn't realize that Robert has died, sometimes confusing other resident's family members with Robert. She often shows caregivers a bracelet that Robert gave her last Christmas and wonders what he will give her this year. She seems to enjoy looking at a photo album her family gave her.

The Situation

Today, Julia has decided that another resident's son is her husband Robert. She joins the resident and her son in the community area and begins asking the son questions about "their" kids and grandkids. When she pats the son on his cheek, the other resident becomes upset. "This is my son, not your husband! Leave us alone!" she says to Julia. Julia begins to cry. The other resident continues to yell and even pushes Julia away from her son.

The Caregiver

CNA Carla steps in to the room and notices the resident speaking loudly to Julia. Carla is aware that Julia doesn't remember that Robert has died and sometimes mistakes others as her husband. Carla is feeling stressed today since another caregiver called in sick and she has more than her share of residents to care for. Frankly, she is weary of Julia approaching every man she sees as if he were her husband. Carla doesn't really blame the other resident for yelling at Julia. She really doesn't have time for all the drama!

Although stressed at the moment, Carla is a dedicated caregiver. She thinks back to her training and decides she must put on her "Crisis Manager" hat. How will she accomplish Steps 1 through 3?

[If possible, break the audience into groups to work together on responses. Encourage them to refer back to the steps in this material and consider the list of unusual behaviors that may cause crisis situations and some barriers that caregivers experience. Ask them to document their responses and be prepared to report back to the group. There are really no "wrong" answers; allow them to practice.]

Step #1 Check Your Own Responses

Step #2 Assess the Situation

Step #3 Take Action or Not?

[Give the audience several minutes to discuss and document their responses. Go round robin to each group or individual to give one thought for each step until all the original ideas have been expressed.]

When we focus on our own reactions and consider the needs of the resident, we are better able to manage crisis situations. Caregivers can feel satisfaction for successfully de-escalating a situation and residents benefit from the support and quality care.

Review the Learning Points

After completing this workshop, learners will be able to:

- Identify behaviors that may lead to crisis situations
- Explain the importance of the caregiver's response
- Create responses based on the needs of the resident
- Manage crisis situations through three major steps

This material was developed by University of Wisconsin Oshkosh – Center for Community Development, Engagement and Training (CCDET) in collaboration with Wisconsin Department of Health Services-Division of Quality Assurance.

Training Materials Checklist

For this training, you will need:

- ✓ Laptop computer (recommended)
- ✓ MS PowerPoint (*PPT Viewer can be downloaded for free at Microsoft.com*)
- ✓ LCD Projector (recommended)
- ✓ Screen for viewing the PPT (recommended)
- ✓ Flip chart and markers
- ✓ Printed Participant Guides
- ✓ Pens or pencils
- ✓ Evaluation (optional)
- ✓ Certificate of completion (optional)

Note: It is strongly recommended that the PPT be viewed using an LCD projector. If that option is not available, the PPT may be downloaded and printed as a handout.